Last Call

When anti-meds veterans must choose between getting sick and taking the cocktail

April 1, 2004 By Nick Williams

I have to confess, when it comes to what a friend calls“woo-woo magic”—psychic surgery, statues shedding tears, levitating gurus, communing with the dearly departed—I’m the opposite of a skeptic. A hot-tub–raised California New Age “bliss ninny”—I’ve been called worse—I was weaned on the axiom that we create our own reality. Indeed, I believed that with healthy eating, positive thinking and probing of deep emotional causes, nary a bugaboo couldn’t be banished.

Until my 30s headaches were borne without the simple solace of aspirin; staph infections were quelled with doses of goldenseal, echinacea and garlic; sprained ankles or broken ribs were queried to reveal their esoteric significance. A trek to the doctor was a last resort, invariably seen as a personal failure: Did I not visualize hard enough, leave some herb unchewed, an age-two trauma unprocessed?

When I became HIV positive, in 1994 at 39, my self-healing impulses revved into overdrive. By 1996, when new AIDS drugs hit the market, the era’s catch-phrase urged: “Hit early, hit hard.” Pharmaceutical companies, doctors and friends encouraged me to join the cocktail party, but my inner voice said “No.” My CD4s were at 800. A year later they took a dip but after more urgings from docs that voice still said “Wait.” Yet swimming against that tide of hype and hope was tough, and I frequently wondered, “Gosh, what if I really am some dumb bliss ninny?”

But before pulling out the heavy guns, I had determined to explore natural alternatives. Consulting books, HIV buyers clubs and the Internet, I investigated—and ingested—dozens of vitamins and supplements of the garden variety: massive multiples, C, E, CoQ10, acidophilus, NAC, alpha-lipoic acid, as well as more exotic (and expensive) thymus extracts, chlorella, Ambrotose and mushroom powders. (I joked that my piss was the most expensive west of the Rockies.) The kitchen reeked variously of Chinese herbs; blended whole lemons, rind and all; everything cooked in coconut butter (yuck!). I plunged into electromagnetic therapy, Sufi spinning, past-life regression work, hypnotherapy. I can’t say how effective each therapy was (I didn’t exactly approach it scientifically), but I did manage to stay med-free for nine years—and at my 30th high school reunion this year was voted “Most Unchanged.” So maybe I’d done something right—or perhaps I was just blessed with good genes.

Sophie’s Choice

Like I did, some HIVers of spiritual and holistic sensibility postpone meds for many years, believing that alternative means might keep the virus at bay. And there's the well-founded fear of side effects, both vainglorious (Will it ruin my modeling career?) and grievous (Will it destroy my liver/kidney/heart?). Besides, who in hell is going to pay for all those platinum-plated pills? Yet even the die-hards can find themselves at that dreaded crossroad, when T cells have dropped to the double digits and all the alternative treatments in the world won't help. When it's time to bite the bullet and ask: Is there a way to integrate meds into my holistic regimen without betraying my body or beliefs?

"I knew little about the various drugs," says Chaz Willow, an artist in Sebastopol, California. "But after watching friends go on new HIV meds and get sick, I didn't want to take them, because I thought they'd kill me." In addition to supplements, Willow delved into fringe-ish healing alternatives: ultraviolet light therapy, ozone therapy, a dirigidoo played over his body and "major juicing." "You knew what I'd been drinking that day," he laughs. "If my skin was purple, it was beets. If yellow, carrots. A green tinge meant collards."

When Sheri Kaplan was diagnosed in 1994, she knew little about HIV and embarked on a crash course. "I wasn't happy with the choices available then—AZT, 3TC and d4T," explains the founder of the Center for Positive Connections, an HIVer support and resource center in Miami offering 30 alternative modalities. "I learned that people can live long if they strengthen the immune system and stabilize stress— which will kill you before anything. I took that route."

Immersing herself in Reiki, acupuncture, kinesiology, healthy eating, visualizations and cranial-sacral therapy, Kaplan succeeded in quashing her 20,000 viral load to zilch. "When my best friend died in a car accident," she says, "I was emotionally destroyed; my viral load shot up to 42,000 and T cells dropped to the low 200s, but I still didn't go on the meds. Call me stubborn."

Another "stubborn" gal who remains true to her beliefs is Andrea Scher of San Luis Obispo, CA, positive for six years, whose CD4 counts recently dropped to 80 (most doctors recommend meds when CD4s are in the 350 to 200 range), followed by hospitalization for shingles and severe eczema. "I am so hard-nosed," she says, fully aware of HIV's seriousness; her brother died of AIDS. "I'm not anti-drugs—I'm just not in a hurry to start the HIV drugs."

Concerned that the meds' toxicity will inhibit her own ability to fight off infections, and about the effects of HIV meds on women, particularly menopausal women like her, Scher lives as healthily as possible. She favors organic food, supplements, Pilates and dancing, and she deals with physical problems as they arise: "When I got bronchitis, I took antibiotics. For me, it was just a red light to chill more."

"I also baby myself, and if I sneeze, I stay home," the 49-year-old artist laughs. "Which I don't mind, because I have so many wonderful things to do here." Colorful masks, sculpture and beadwork fill her apartment.

Doctor Strange Love

Whether or not I began the meds, I wanted a doctor who wouldn't dismiss my holistic perspective as voodoo. So did Willow. "I was clear I'd only work with a doctor capable of also nurturing my spirit," he recalls. "When I first visited my doctor, I asked him to place his hand on my heart and talk to my life force. And he did."

That physician was Scott Eberle, MD, in Santa Rosa, CA, who explains that he "grew up" as an AIDS doc in the late 80s when there was little to offer except an abiding respect for a patient's commitment to life and ultimately death. "Lessons learned at the bedside continue to inform how I relate to people with a chance to live," Eberle says. "Any regimen's success—defined not just by lab results but by the ability to cope with side effects, fitting drugs into your lifestyle, not missing doses—begins with a person's belief in the rightness of that choice.

"I believe that all health choices belong to the person whose well-being I'm called to serve," Eberle adds. "My job is to educate and support. I will offer honest feedback about a decision I consider misguided, but ideally I'm respecting their right to make that decision."

Jon Kaiser, MD, a San Francisco AIDS specialist and author of Healing HIV: How to Rebuild Your Immune System, espouses a similar approach: "It's important to establish a strong bond with patients so they don't feel they're being railroaded into prematurely taking antivirals before trying everything else."

Kaiser routinely works with natural methods to stabilize the immune system, incorporating seven strategies: taking effective antioxidant therapy; maintaining optimal muscle mass through protein supplements, exercise and sometimes anabolics; aggressively treating herpes; screening for/eradicating intestinal parasites; correcting imbalances in testosterone and DHEA; and reducing stress.

"My role is also to inform about the unsafe boundaries," Kaiser says. "You don't want to wait until CD4s drop under 200 or 300, because then when you go on meds you'll experience more side effects, and there's increased risk of OIs."

If, after employing the above methods, CD4 cells head too far south, Kaiser says, "I give my patients a 95-percent guarantee that with a continued natural program and intelligently selected antivirals, their viral load will go down and CD4 cells will go up, they'll experience minimal side effects, and they'll feel as good or better than before. That gives them a lot less to worry about before starting." (See "What's the Alternative" below)

Sleeping with the Enemy

Over the years, as I experimented with new supplements (carnitine, quercetin and olive leaf extract) and some way-out therapies (don't ask), I dutifully monitored my CD4 count—a slow, steady decline. By June 2003, it had dropped to 240, and it was time to reconsider. Three months later, a drop to 175 and the cocktail shaker was off the shelf. With a plummet to 75 the next month, I was ready to begin.

I didn’t see it as a failure of the alternatives—or of myself, as I would have in the past. Granted, my change of perspective came of necessity, but I began to see that meds might complement my other therapies rather than compromise my health. I’d spent years dreading the day I’d depend on drugs for survival, but the vibration of fear is not conducive to healing and certainly would not be optimal for the substances I was about to ingest. It behooved me to transform my foreboding into welcoming. So I planned a weekend honeymoon of gently introducing the triple combo into my energy field. What better way to get to know someone than to sleep with them? I crawled into bed that first night, tucking the pills into my boxers, and slept.

The next morning, with the new prescriptions nestled among the crystals, sea shells and sage on my altar, I meditated for an hour with the pills in my palm, tuning in to the myriad brain synapses that created them; the millions of dollars invested; the friends who had passed on before the advent of the drug. … Yes, I believe in miracles of the esoteric sort, yet I also came to understand that these pills were a miracle of a more prosaic nature.

Kaiser suggests a similar exercise for patients with drug dread: “Hold the pills in your hand—do this with each dose for a week or so—get comfortable with them, get mindful of this beneficial therapy and invite the meds into your body to bring the load down and to help you heal.” He explains that the meditation won’t necessarily prevent side effects but may lessen the fear, which can contribute to diarrhea, headaches and rash.

Willow held out until the bitter end. His weight dropped from 160 pounds to a skeletal 112, and he was falling asleep at work. “I didn’t choose drugs because I was afraid of dying but because maybe I had more work to do,” he recalls of that time at death’s doorstep. “I realized my alternative treatments needed balance. I understood that these HIV drugs embody thousands of years of alchemy and that somewhere in them are plants, minerals and the souls of friends who had died. It wasn’t just a prescription I was given, but a different relationship to spirit.”

Gestalt exercises with a therapist helped Willow over the hump. “Personifying the meds on a chair,” he said, “I talked to them, saying things like, ‘I’m afraid you’ll kill me,’ ‘I’m worried you’ll make me look ugly’ and ‘I want you to help me live longer.’” Willow drew pictures and made sculptures, which fill his house and yard, of his relationship to the meds and the virus.

Despite his creative efforts, in that hellish first week Willow repeatedly coughed up the meds, resorting to anti-nausea suppositories. But within six weeks, his health improved. Despite the collective horror of September 11, 2001, that day became a hallmark for Willow. “When I came into the clinic, I wasn’t walking with my cane. I felt like the Phoenix Rising.”

Scher has allotted herself a month to recover from shingles (she’s taking Zovirax and a PCP-preventative drug), educate herself and weigh the options. To expand her knowledge base, she’s kibbitzing by phone with other HIV positive women—some on meds, others not. And she feels comfortable with her new doctor. “I’m open to hearing what she thinks I should do,” Scher says. “My belief system has had to expand way beyond what I previously imagined. My road has come to a fork, and I’m open as long as I can stay out of my fear.”

With Kaplan, so far so good. “I’m healthy, and my quality of life is excellent. My T cells are in the 250s and viral load (30,000) is under the guidelines. I’ve never been an A-student, so I’m happy with where I’m at,” she laughs, contending that her busy life doesn’t leave time to deal with a pill burden and possible side effects. “I do what I must to stay healthy. I’ll save the armed forces [meds] for when I need to pull them in.”

My first month on meds was no holiday. Food became repulsive, and I lost weight; some days I hardly roused from bed; and life slowed to a crawl. Switching from AZT to Viread finally gave me that needed perk, and life gradually resumed. While dutifully downing the pills, I still use alternative methods, ever mindful that, as Kaiser wrote, “Healing doesn’t take place in a bottle.”

Through all this, I learned to question everything, educate myself, explore various options, then go within and trust my inner voice. And I learned that miracles, big and small, happen everyday—but that my current choices may not work forever. My mantra: Be ever-ready for change.

What’s The Alternative?

POZ’s red-ribbon panel lays down its list of holistic picks:

>> Books

Healing HIV: How to Rebuild Your Immune System
by Jon Kaiser, MD.
(Healthfirst Press/Mill Valley, CA), $19.95

Built to Survive: A Comprehensive Guide to the Medical Useof Anabolic Steroids, Nutrition, and Exercise for HIV (+) Men and Women
by Michael Mooney and Nelson Vergel
(Program for Wellness Restoration, Houston), $20.95

Nutrition and HIV: A New Model for Treatment

by Mary Romeyn, MD.
(Jossey-Bass Inc. Publishers/San Francisco), $20

The HIV Wellness Sourcebook: An East-West Guide to Living Well with HIV/ AIDS
by Misha Ruth Cohen, OMD, LAC.
(Henry Holt/New York), $14.95

Encyclopedia of Nutritional Supplements
by Michael Murray, ND.
(Prima Publishing/Rocklin, CA), $19.95

Staying Healthy with Nutrition: The Complete Guide to Diet and Nutritional Medicine
by Elson M. Haas, MD.

(Celestial Arts, Berkeley), $39.95

>> WEB SITES

Buyers clubs, fact sheets and treatment info:

Direct Access Alternative Information Resources
www.daair.org

Houston Buyers Club
www.houstonbuyersclub.com

American Botanical Council
www.herbalgram.org

The Body
www.thebody.com/treat/altern.html

Critical Path AIDS Project
www.critpath.org

Herb Research Foundation
www.herbs.org

Jon D. Kaiser, MD's site (and newsletter)
www.integrativehealthconsulting.com/

Medibolics
www.medibolics.com

The New Mexico AIDS InfoNet
www.aidsinfonet.org (click on "fact sheets")

Positively Well
www.larklands.net

>> NEWSLETTERS

AIDS Treatment News
1233 Locust St., Floor 5,
Phildelphia, PA 19107; 215.546.3776
www.aids.org/atn

Treatment Update & The Positive Side
Canadian AIDS Treatment Info Exchange (CATIE)
555 Richmond St. W., Suite 505, Box 1104

Toronto, ON M5V 3B1 Canada
416.203.7122; 800.263.1638
www.catie.ca (also publishes fact sheets)

Treatment Issues

Gay Men's Health Crisis
The Tisch Building
119 W. 24th St.
New York, NY 10011
212.367.1000
www.gmhc.org/health/treatment/treatment_issues.html

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